PERCEPTIONS OF HIV AND FERTILITY AMONG ADOLESCENTS IN SOWETO, SOUTH AFRICA: STIGMA AND SOCIAL BARRIERS CONTINUE TO HINDER PROGRESS

by

Jamie I. Forrest BSc, University of Guelph, 2007

PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF PUBLIC HEALTH

In the Faculty of Health Sciences

© Jamie I. Forrest 2009

SIMON FRASER UNIVERSITY

Spring 2009

All rights reserved. This work may not be reproduced in whole or in part, by photocopy or other means, without permission of the author.

APPROVAL PAGE

STUDENT'S NAME:	James Forrest
DEGREE:	MASTER OF PUBLIC HEALTH
THESIS TITLE:	PERCEPTION OF HIV AND FERTILITY AMONG ADOLESCENTS IN SOWETO, SOUTH AFRICA: STIGMA AND SOCIAL BARRIERS CONTINUE TO HINDER PROGRESS
Chair Of Defense:	Dr. Steve Corber Associate Professor, Director Public Health Pract. Faculty of Health Sciences
Senior Supervisor:	Dr. Bob Hogg Professor Faculty of Health Sciences
Supervisor:	Dr. Cari Miller Assistant Professor Faculty of Health Sciences
External:	Dr. Susan Erikson Assistant Professor Faculty of Health Sciences
Date Defended / Approved:	March 23, 2009



Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the "Institutional Repository" link of the SFU Library website <www.lib.sfu.ca> at: ">http://ir.lib.sfu.ca/handle/1892/112>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author's written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library Burnaby, BC, Canada

ABSTRACT

The scale up of highly active antiretroviral therapy (HAART) has raised new concerns regarding stigma associated with HIV and childbearing. High rates of infection and fertility make adolescents a crucial demographic to qualify perceptions of HIV and childbearing. Two focus groups were conducted with participants ascertained from an HIV adolescent community advisory board in Soweto, South Africa. Grounded theory, as a method of qualitative analysis was used to draw thematic conclusions. Adolescents raised concern over re-infection by HIV positive couples and justified the attitude that infected partners should adopt when faced with fertility desire. Also, participants spoke of a need to revise adolescent sexual and reproductive health services in a way that addresses stigma generated by community healthcare workers. This study should be used as preliminary findings to guide future research, both qualitative and quantitative, which further explores motivations for negative attitudes towards HIV and childbearing.

Keywords: HIV; Fertility; Adolescents; Childbearing; Stigma; South Africa

Subject Terms: HIV infections -- Africa, Sub-Saharan; Fertility -- Africa, Sub-Saharan; Pregnancy in Adolescence -- South Africa -- Congresses; Teenagers -- Sexual behavior -- South Africa

DEDICATION

I dedicate this stepping stone to family – To my parents, Don and Sue, Michelle and Lisa, for their continuous support and guidance of my unremitting academic pursuits. Unquestionably, your love and support has helped foster my achievements. – To my sister Kaitlin, for keeping me grounded and always reminding me that there are many ways to understand life. Lastly, – To George. Your presence and companionship in Vancouver has rooted, for me, the importance of family, wherever I travel.

ACKNOWLEDGEMENTS

First, I graciously thank the focus group participants for their insightful contributions to this field of research. Without these participants, this study would not have been possible. I also thank Ms Mamakiri Khunwane, Mrs. Phindile Maseala and Mr. Sipho Mazibuko for their generous help facilitating the focus group discussions, as well as with transcription and translation of the data.

Secondly, I thank Mr. Helgard Marais and Mrs. Heather Humphreys for their kind hospitality in Johannesburg, South Africa throughout the data collection and practicum placement. I would also like to thank Ms Angela Kaida, as well as Ms Janan Dietrich as Drs. Glenda Gray and Fatima Laher from PHRU for their academic guidance, support and encouragement while in the field and upon return to Canada

Lastly, I extend gratitude to my committee members. Thank you to my supervisors Drs. Robert S. Hogg and Cari L. Miller as well as my external reviewer, Dr. Susan L. Erikson and the chair of my defense Dr. Steve Corber. Your insightful contributions to my Masters project have been invaluable.

TABLE OF CONTENTS

Approval	ii
Abstract	iii
Dedication	iv
Acknowledgements	v
Table of Contents	vi
List of Tables	viii
Glossary	ix
Introduction	1
Background	3
HIV in South Africa	
Fertility in the Context of HAART	
Reproductive Intentions of HIV-positive Women and Men	
Stigma Associated with HIV and Childbearing	
Methods	7
Study Setting	
Participant Eligibility	
Data Collection	
Focus Group Discussions FGD Question Content	
Scenario 1	
Scenario 2	
Data Analysis	10
Results	12
Community Attitudes Towards Childbearing	14
Attitudes on HIV and Childbearing	15
Barriers to Accessing Services on HIV and Childbearing	16
Discussion	18
Limitations	20
Conclusions and Further Research	24
Adolescents as a Crucial Age Demographic	24
Future Research	25
Theoretical Framework to Consider	26

Reference List2	28
-----------------	----

LIST OF TABLES

Table 1.	Demographic of	characteristics of t	focus group	particip	oants	13

GLOSSARY

AIDS Acquired Immune Deficiency Syndrome

ART Antiretroviral Therapy

ARV Antiretrovirals (HIV drugs)

FGD Focus Group Discussion

HAART Highly Active Antiretroviral Therapy

HIV Human Immunodeficiency Virus

MTCT Mother-to-child Transmission of HIV

PEPFAR President's Emergency Plan for AIDS Relief

PHRU Perinatal HIV Research Unit, Soweto, South Africa

USAID United States Agency for International Development

VCT Voluntary Counselling and Testing

INTRODUCTION

A decade ago, many nations in sub-Saharan Africa afflicted by the HIV/AIDS pandemic were coping with limited access to antiretroviral therapy (ART). Since that time, access to antiretrovirals (ARVs) has substantially increased in many parts of sub-Saharan Africa (Joint United Nations Programme on HIV/AIDS, 2008). This scale up of highly active antiretroviral therapy (HAART) has raised new issues relating to fertility desires and outcomes (Kaida et al., 2006). In sub-Saharan Africa, HIV is predominantly transmitted through heterosexual intercourse, resulting in risk factors that share a common pathway for both HIV transmission and pregnancy. One of the many concerns associated with fertility in an era of effective treatment are negative attitudes and resulting stigma associated with childbearing in the context of HIV.

The issue of childbearing concerns in the context of HIV lies disproportionately among young women who are at the greatest risk of becoming infected at a time when many contemplate and act upon their fertility desires. In 2007, 12.9 percent of young South Africans aged 15-19 years were infected with HIV (National Department of Health, South Africa, 2008). Additionally, childbearing among this age group also remains high. One in three South African girls have become pregnant by age 20 (Kaufman, de Wet, & Stadler, 2001) and 13 to 16 percent of these pregnancies have occurred among HIV-

infected women (National Department of Health, South Africa, 2008). By the age of 24, half of all South African women will have become pregnant at least once. With such a high prevalence of both HIV and fertility in South Africa at a young age, it is thus timely that research uncovers the perceptions of HIV and childbearing among this crucial age demographic. This study aims to qualitatively characterize the attitudes towards HIV and childbearing among the adolescent community of Soweto, South Africa.

BACKGROUND

HIV in South Africa

South Africa has one of the fastest growing HIV epidemics in the world. In 1990, approximately one percent of pregnant women were HIV positive (National Department of Health, South Africa, 2008). In 2005, an estimated prevalence of 30 percent of pregnant HIV positive women was reported. This drastic increase in infection rates has resulted in the country having the largest population of HIV positive people in the world, with an estimated 5.5 million people or approximately one in eight living with the disease (National Department of Health, South Africa, 2008).

South Africa's HIV/AIDS epidemic came into the limelight in the 1990s and early 21st century when key figures of the South African Government, including then President Thabo Mbeki, began challenging the global conventional views of HIV/AIDS. Official government documents were circulated that posted the primary role of poverty and other socio-economic stressors on the progression of the AIDS epidemic. These positions had detrimental effects for AIDS policymaking and ultimately resulted in a delayed implementation of a national ARV rollout. Furthermore, this denialism resulted in the gross propagation of AIDS stigmatization and misinformation. A study conducted in a South African township in 2005 compared levels of stigma across the one-year period in which ARVs became available (Forsyth, Vandormael, Kershaw, & Grobbelaar, 2008).

Participants of the study who endorsed the contentious political views shared by many members of the South African Government were more likely demonstrate higher levels of AIDS-related stigma than those who disagreed. This suggests that the uniqueness of South Africa's epidemic must be addressed when exploring community attitudes related to HIV.

Fertility in the Context of HAART

In sub-Saharan Africa, approximately 14 million women of childbearing age are living with HIV/AIDS (Joint United Nations Programme on HIV/AIDS, 2008). Two articles reviewing the relationship between HIV and fertility in sub-Saharan Africa have concluded that women with HIV infection have a lower fertility than non-infected women for most age groups (Lewis, Ronsmans, Ezeh, & Gregson, 2004; Zaba & Gregson, 1998). Several reasons explain this relationship, including the direct biological effects of HIV on the fecundity of infected women and the indirect impact the virus has on behavioural determinants of fertility.

Pharmacological advances in the prevention and control of mother-to-child transmission (MTCT) of HIV, coupled with an improved global political commitment to treatment have resulted in a substantial reduction in the rates of vertical transmission of the virus. In fact, the success of HAART has reduced MTCT rates to approximately 1-2 percent (Volmink, Siegfried, van der Merwe, & Brocklehurst, 2007). With these new interventions, incident HIV infections in children are becoming increasingly rare in many parts of the world, including Soweto. Additionally, with appropriate treatment that reduces an infected

individual's viral load to an undetectable level, there is little to no risk of HIV seroconversion among serodiscordant couples engaging in unprotected sex for the purpose of conception. These advances have thus raised new questions about the relationship between HIV and fertility in a new era of accessible treatment (Kaida, et al., 2006).

Reproductive Intentions of HIV-positive Women and Men

Despite decreases in actual levels of fertility, HIV positive men and women continue to express their desire to have children. A 2007 study in South Africa demonstrated that fertility desire was significantly associated with an increase in duration of HAART (Myer, Morroni, & Rebe, 2007). This finding may indicate that a woman's desire for fertility is more likely to be prioritized once disease management has been achieved. Qualitative data on fertility intentions among HIV positive women cite family, husbands' and societal expectations for childbearing that influence a woman's reproductive intentions. Furthermore, these motives often counterbalance HIV as a factor discouraging reproduction (Cooper et al., 2007). However, despite these expressed desires, most HIV positive women are not discussing their reproductive intentions with healthcare providers in HIV care or general health services because of anticipated negative reactions. Cooper et al., (Cooper et al., 2007) further qualify that the few women who had done so, perceived the counselling environment to be mostly unsupportive of the complex issues related to fertility decision-making in the context of HIV.

Attitudes and Stigma Associated with HIV and Childbearing

Few studies have explored the direct relationship of attitudes and perceived stigma in the context of HIV and childbearing. Research in the United States suggests that high levels of disclosure-related stigma produce an 18.6 percent decrease in the odds of a woman with HIV choosing to become pregnant (Craft, Delaney, Bautista, & Serovich, 2007). In South Africa, Myer and colleagues (Myer, Morroni, & Cooper, 2006) demonstrated that childbearing and HIV also remains highly stigmatized. These authors concluded that negative attitudes towards HIV and fertility, as well as negative attitudes towards sexual activity among HIV infected individuals, were significantly associated with not knowing someone who is HIV positive. The former was also significantly associated with not having had an HIV test. Among adolescents, who comprise the future of the response to the HIV pandemic, these attitudes have not been uncovered, thus far in academic literature.

METHODS

Study Setting

Soweto is a collection of townships with a population of approximately 3,000,000 located 15 kilometres southwest of the city of Johannesburg (City of Johannesburg, 2008). This study was conducted from April to July of 2008 at the Perinatal HIV Research Unit (PHRU) located at the Chris Hani Baragwanath Hospital in Soweto, a research division of the University of Witwatersrand in Johannesburg. The PHRU is one of Africa's largest HIV/AIDS research and clinical service centres. The PHRU clinic sees over 5,000 patient visits monthly and provides ART and clinical care to medically eligible HIV positive individuals. Additionally, the PHRU offers on-going wellness care for those not yet medically eligible for ARVs. In addition to the clinical and research activities, the PHRU operates a Prevention Studies area that includes a Voluntary Counselling and Testing (VCT) centre. All PHRU services are free of charge and programme costs are largely funded by USAID, PEPFAR and other bilateral donor agencies.

This research was conducted as part of a collaborative agreement between Simon Fraser University and PHRU as part of practicum placement by the author. The study topic was chosen by key figures at PHRU who perceived this subject as important, timely and accomplishable during a three month placement period.

Participant Eligibility

Participants were recruited through an adolescent community advisory board established at the PHRU. Community advisory board members were asked to recruit other members of their peer group who may be interested in participating. Eligibility criteria included aged 16-18 years and residing in Soweto. HIV status was measured by self-report at the time of participant recruitment. Being sexually active was not inclusion criteria for participation in this study. Participants were required to sign a consent form to participate in the study and parental consent was sought for all participants under the age of 18 years. No adolescents or parents refused consent for participation in this study. Ethics approval for this study was given by the Research Ethics Boards of the University of Witwatersrand in Johannesburg and Simon Fraser University in British Columbia, Canada (see attached ethics approval forms from SFU Research Ethics Board).

Data Collection

Data was collected by trained facilitators in a meeting room at the Chris
Hani Baragwanath Hospital, located in the Diepkloof suburb of Soweto.

Participants were asked to complete a brief demographic questionnaire that elicited information on age, household demographics and future fertility desires.

In total, two focus groups were conducted: one with male participants and the other with female participants.

Focus Group Discussions

Each focus group discussion lasted approximately 1.5 hours. The interview guide/moderator's guide for the FGD was semi-structured based on a pre-designed focus group moderator's guide. Eleven males participated in the first focus group while eight females made up the second. Both focus groups were conducted in English with participants invited to respond in the language that they were most comfortable speaking. While the moderator of the focus group spoke only English, a note taker for each focus group, fluent in Zulu and Sotho (local languages of Soweto), assisted the moderator in simultaneous translation of the discussion.

FGD Question Content

FGD questions addressed primarily attitudes of adolescents towards HIV and childbearing. General attitudes towards childbearing and HIV were assessed with the following questions:

- Can you tell me your thoughts about having children in the future?
- Who encourages you to have children?
- How does your community feel about adolescents who fall pregnant?
- What does your community think about people who are HIV positive?
- How might you think pregnancy would be different if you were HIV positive?
- How would someone access information on pregnancy and HIV in Soweto?

Perceptions of HIV and childbearing were further explored by stimulating discussion with the following two scenarios written in plain language to ensure comprehension among adolescent participants:

Scenario 1

A 17-year-old girl who knows she is HIV positive sees a doctor because she thinks she might be pregnant. She is not currently taking medication for HIV. The doctor confirms the girl is pregnant. She is worried about her health and the health of her baby and seeks counselling to help understand her concerns.

Scenario 2

A 25-year-old woman and her husband want to have a child. They are both HIV positive but have both been taking treatment for three years and both feel very healthy. Their community and family know they are both HIV positive and the couple has also heard there is treatment to prevent the woman from passing the virus to her unborn baby. However, they are still very concerned about the health of their unborn child and what the community may think about them falling pregnant.

Data Analysis

Each FGD was audio recorded and transcribed verbatim. Where a local language was used, the discussion was translated into English. Transcripts were analyzed for key qualitative themes using the analytical formula of Grounded Theory (Corbin, Strauss, & Strauss, 2008; Walker & Myrick, 2006). Grounded Theory, as a method of qualitative analysis manages words, language and the

meanings they imply (Miles & Huberman, 1994). The brilliancy of this method of analysis is in its capacity to create rich descriptions and understandings of social life. The procedure has a well-defined process that begins with basic description and moves to conceptual ordering and finally to thematic conclusions and theory (Walker & Myrick, 2006). Each of the three thematic categories presented in the results were drawn out of transcript analysis. A common code system was generated, which was revised several times as coding proceeded. This coding system was used to identify key quotes from each transcript, which fell within thematic categories identified through qualitative analysis. Quotes below are presented verbatim and are identified with their study ID number.

RESULTS

Table 1 shows demographic characteristics of the male and female focus group participants. Eleven males participated in the first focus group and eight females in the second. The median number of household members per participant was seven. In total, four participants (21%) reported that a member of their household was currently pregnant and another four participants (21%) reported having household members who have disclosed a positive HIV status. The vast majority of participants expressed the desire to have children in the future. Two participants (11%) expressed a desire to never have children while two other participants (11%) were undecided at the time of questionnaire completion. All study participants self-reported as HIV negative.

Table 1. Demographic characteristics of focus group participants

		Males		Females		Total
		(Focus group 1)		(Focus Group 2)		
		N	%	n	%	
Total number of participants		11		8		19
Age	16	4	36	0	0	4
	17	5	45	4	50	9
	18	2	18	4	50	6
Median number of household members		8, Range= [3,13]		5.5, Range= [4,7]		
Number of	0	7	64	7	88	7
household members	1	3	27	1	13	4
pregnant	Missing	1	9	0	0	1
Number of	0	8	73	4	50	12
household members	1	0	0	0	0	0
with HIV	2	0	0	2	25	2
	3	1	9	0	0	1
	4	0	0	1	13	1
	Missing	2	18	1	13	2
"Would you	Yes now	0	0	0	0	0
like to have a child?"	Yes in the future	10	91	4	50	14
	Never	0	0	2	25	2
	Undecide d	0	0	2	25	2
	Missing	1	9	0	0	1

Theme 1: Community Attitudes Towards Childbearing

Participants were asked about how their community feels about having children. Participants believed that having a child is a crucial part of life. As one female participant stated:

"I think it's about having future generations...just continuing the generation and knowing that there is another person leaving your legacy behind." [ID No.: F02, 17-year-old female]

Most participants agreed that while "accidents" can sometimes happen, the choice to have a child is almost always made by the mother. However, one participant added that some girls in Soweto are not always given the choice to have children. In South Africa, all women who have children under six years of age are entitled to a child care grant called the "Child Support Grant". She explained:

"There's girls that have babies for grants sake. There are some places where poverty is very high. Now if there is girls in the house and the mother is really struggling to take care of the rest of kids...she will tell the girl to go make a baby and then she will get the grant and that grant will be used for stuff in the house." [ID No.: F05, 18-year-old female]

Speculation is rife in South Africa about the association between teenage pregnancy and the Child Support Grant. Research undertaken in 2006, by the Government of South Africa, Department of Social Development failed to show any link between teenage pregnancy and uptake of the Child Support Grant.

Both male and female participants agreed that having a child as a teenager

would be both unacceptable by the Sowetan community and not consistent with personal values.

Theme 2: Attitudes on HIV and Childbearing

Two major themes emerged with regards to HIV and childbearing in response to the scenarios. First, participant's primary concern with couples having children who are HIV positive was their risk of re-infection as illustrated by the following quote from a male participant:

"They should be very worried because they are going to re-infect each other with this virus and then they will leave the treatment unable to work and they will give themselves the risk of getting more sick." [ID No.: M02, 18-year-old male]

Secondly, participants also expressed that adoption would be a much better option for this couple than trying to have a child. The following quote by a male participant highlights the feelings of most focus group members in response to the second scenario:

"I think what is best for them is to adopt a baby because when they will have a newborn baby, what if after four years they are going to die and then the baby will still be a child." [ID No.: M10, 17-year-old male]

Adoption was further supported by many participants' fears that the couple would re-infect each other. Another male participant defended the position of the group by saying:

"I think it is right to adopt because they have HIV and AIDS and to my opinion they must adopt because they should think that the

more they have unprotected sex the more they reach AIDS through re-infection" [ID No.: M01, 16-year-old male]

Re-infection or "superinfection" is a common topic amongst HIV infected adults in Soweto. There is a belief that if someone has unprotected sex with another HIV infected individual, they may become re-infected or "superinfected" with a different viral strain that can render ART ineffective.

Theme 3: Barriers to Accessing Services on HIV and Childbearing

Participants unanimously agreed that Soweto lacks youth-friendly services and public clinic nurses generate much of the stigma surrounding the issue of HIV and childbearing. One participant noted:

"In Soweto, we have a youth clinic that is situated in Kliptown called Kygana Motsha and it is a place that I have been going a lot. The services are very good and they do not judge you. I prefer to go there for my information than any other public clinic where there is everyone there because the nurse might as well tell me in front of everyone, you are HIV positive and dying, you have AIDS, you can't have children. Just go home and sleep, you don't need children." [ID No.: F06, 18-year-old female]

Another female participant added:

"Nurses in Soweto do not treat you like human beings. They stigmatize you and by the time you leave there you just have a different mindset. If you came happy because you are wanting to find information on being HIV positive and wanting to have a child, the nurse will come there, and maybe she pretends to

be your mother so she gives you this long lecture on how you are not supposed to have children." [ID No.: F04, 17-year-old female]

Participants expressed their desire for more youth friendly services where they can receive advice from people their own age who will not judge them for their behaviours. One participant's final comment in the focus group stated:

"What I feel, is that Soweto needs more clinics like Kygana Motsha where there are teens who are speaking to people they feel are at their level. I mean if you go to the community clinic, I don't want to speak to old ladies about my problems because then she speaks to me like she is my mother...So if that would be implemented then more things would change in Gauteng as a whole or maybe even worldwide." [ID No.: F04, 17-year-old female]

DISCUSSION

This study qualitatively reports the perceptions of adolescents who regard themselves as HIV negative, on the topic of childbearing and HIV. This topic is of particular importance to adolescents who reside in a country where more than one in ten adults is HIV infected (National Department of Health, South Africa, 2008). This is also the first study to report these perceptions, specifically among adolescents. This study adds to the growing body of literature on HIV and fertility. It presents three key themes of importance to the field of fertility and HIV. First, participants in both FGDs perceived unprotected sex among HIV positive couples as a serious threat to the progression of their disease. The threat of re-infection was stated as the most important reason why HIV positive couples should not try to conceive. This level of concern about a process called HIV superinfection is perplexing. Although, the scientific community appears to have reached little consensus on this topic (Smith, Richman, & Little, 2005), recent literature may suggest that HIV superinfection is more common than once thought. Piantadosi et al. (Piantadosi, Chohan, Chohan, McClelland, & Overbaugh, 2007) detected seven cases of HIV superinfection in a cohort of 36 high-risk Kenyan women. However, regardless of a true prevalence of HIV superinfection, the authors suggest that this data has far greater implications for vaccine development than for individual disease management. This would suggest that the issue of HIV superinfection needs to be redressed among

Sowetan youth in light of the fact that HIV superinfection is still not of enough concern to justify an abstention of conception among HIV positive couples.

Secondly, adolescents in both focus groups felt adoption would be a much better option for an HIV positive couple wanting to have a child. Participants also often used re-infection as support for adoption. Members of each focus group also supported their attitudes of adoption by saying parents would not want to have kids when they are ill. However, Ezeanolue and colleagues (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006) quantitatively assessed sexual knowledge, behaviours and fertility intentions of adolescents with perinatally acquired HIV in the United States. Among the 50 participants who were aware of their HIV diagnosis, 70 percent expressed intent to have children. The authors concluded that fertility intentions were highest among those adolescents who perceived the risk of mother-to-child transmission as low. This suggests that perhaps more education on the fertility options of HIV positive women, attitudes towards childbearing and HIV may change.

Lastly, participants highlighted their concern that progress surrounding childbearing and HIV continues to be hindered by attitudes of community healthcare workers. The issue of healthcare worker stigma requires further research and discussion within the South African context and appears to be a requisite for overcoming community stigma surrounding HIV and childbearing. Although the reasons for negative attitudes by healthcare workers were not explored, a lack of healthcare worker knowledge on the subject of HIV and childbearing, consistent with many studies across sub-Saharan Africa, may

be a contributing factor to the generation of this stigma. In a 2006 Nigerian study by Sadob *et al.* (Sadob, Fawole, Sadoh, Oladimeji, & Sotiloye, 2006) only 77 percent of nurses surveyed correctly identified breastfeeding as a mode of HIV transmission. A second study in a Madagascar context, demonstrated that only nine percent of healthcare workers were aware of HIV transmission through breastfeeding and 73 percent were unaware of any interventions to prevent mother-to-child transmission (Hentgen, Jaureguiberry, Ramiliarisoa, Andrianantoandro, & Belec, 2002). More research on knowledge of HIV and childbearing is needed in a Sowetan context, which may corroborate this study's qualitative description of healthcare workers' negative attitudes.

Participants also spoke about their desire for more youth-friendly sexual health services. Particularly, participants appealed for services that may eliminate the stigma that their HIV positive peers may face when trying to access information on HIV and childbearing from community clinics. Kipp and colleagues (Kipp, Chacko, Laing, & Kabagambe, 2007) highlighted this barrier in Uganda where sexual and reproductive health services were not adequately tailored for young people. These authors called for a redress of programs, which target healthcare worker attitudes in addition to increasing the confidentiality and privacy of clinic users.

Limitations

Members of a local Sowetan community advisory board on HIV were asked to be participants in this study, which perhaps added an additional filter of information to this study. Convenience sampling from this population was used

to gain valuable insight from youth who have pre-existing knowledge of the services and social climate surrounding HIV and fertility. The adolescents of this study were only able to comment on their perceptions of HIV and fertility because they had a background on the subject and perhaps youth selected at random from the community may not have been able to provide as much insight into the topic. Additionally, access to the adolescent population at large was not possible without the avenues and connections to the youth community of Soweto that take time to appropriately establish. As such, it has been recognized that these results can not be generalized to the entire adolescent Sowetan population, thus this research, while beneficial to guide and support future studies, requires additional qualitative and quantitative validation.

Additionally, although this study only qualitatively evaluated the perceptions of adolescents from two focus group discussions, a thick, narrative description has been presented. In this study, the author is confident that data saturation was reached to adequately describe issues relating to the important topic of adolescent perceptions of HIV and childbearing with the number of participants available for study. This evidence can be used to support future quantitative and qualitative studies that acknowledge the stigma and social barriers hindering the progress of issues relating to HIV and fertility.

This study also asked adolescent participants to self-report their HIV status. While all participants reported their status as negative, this may not be a reflection of their true HIV status. Testing rates in South Africa among adolescents remain low. In 2004, only 11 percent of HIV positive young men and

19 percent of positive women reported knowing their status (Pettifor et al., 2005). It is also well documented that many social barriers continue to delay young people from seeking voluntary counselling and testing (VCT) (MacPhail, Pettifor, Coates, & Rees, 2008). However, while participants' actual status may not be concordant with their reported status, this should have no effect on their perceptions of HIV and fertility. Participants who believe their status to be negative would thus share their attitudes from an HIV negative lens. This study also recognizes that in light of this, response bias may have clouded this data. In an attempt to minimize the influence of response bias, participants were assured by both the moderator and the translator, that there were no right or wrong answers and that their experiences and attitudes would not be judged by any member of the research team.

Lastly, this study failed to ascertain data from the study participants on sexual activity and behaviour. Particularly, characteristics on sexual activity and choice of contraception would be of use to further qualify the relationship between HIV, sexual behaviour and fertility attitudes. In 2004, Simbayi *et al.* (Simbayi, Chauveau, & Shisana, 2004), reported that in a multi-stage cluster sample of 2,430 South African adolescents, the median age of sexual debut was 16.5 years and with very little variation by sex. These data indicate that it was safe for this study to assume that in two focus groups of 19 adolescents aged 16-18 years, a number of participants would have sexual experience, which may contribute to an exploratory analysis of the attitudes of childbearing in the context of HIV. This research was not able to explore issues relating to participant

sexual behaviours. However, future research should incorporate this important topic into the research agenda. Additionally, to avoid overlap with other studies currently being conducted at PHRU specifically exploring sexual behaviour and HIV in the same age demographic, this study chose to explore only attitudes on childbearing in the context of HIV.

CONCLUSIONS AND FURTHER RESEARCH

Adolescents as a Crucial Age Demographic

Adolescents are of critical importance for sexual health interventions worldwide and in South Africa explicitly. This age group not only represents the most under-serviced and under-researched of populations, but also a demographic that is most at risk of receiving inaccurate HIV education and reproductive advice. A lack of researcher integrated adolescent social networks and strict ethical guidelines may unintentionally be silencing young people who most need to have a voice in sexual and reproductive health research (Flicker & Guta, 2008). Additionally, consolidating existing HIV services for adolescents with existing sexual and reproductive health services may ease the recruitment and access of adolescents for future research. It is imperative that this age demographic receives evidence-based knowledge and interventions that are tailored to meet their unique needs.

Qualitative data from this study suggests two opportunities to impact adolescents specifically. First, data indicate a need for reviewing the current practices of HIV education in Soweto. Particularly, a knowledge update and consensus on HIV superinfection prevalence and disease management, as well as the successes of ARV therapies in reducing viral transmission are key messages that appear to be missing or understated in youth HIV education.

Secondly, these data advocate specifically for a scale up of youth-friendly sexual

and reproductive health services that include peer support and healthcare workers trained specifically to work with an adolescent population.

Future Research

This study should be used as preliminary data to inform and guide future research. There are two elements of this study that require further research to clarify the topics discussed in this study. First, these perceptions must be uncovered among HIV positive youth of similar demographics. A study of this nature will further qualify these perceived negative attitudes in the context of internal and received stigma. Furthermore, these attitudes need to be quantified to better understand the impact that childbearing and HIV stigma may have on various outcomes in adolescents. Administering a questionnaire with a validated HIV stigma scale, such as the widely used Berger *et al.* (Berger, Ferrans, & Lashley, 2001) scale, may be a very useful tool to help quantify these perceptions.

Secondly, the attitudes expressed by adolescents towards community healthcare workers need to be explored further. Healthcare providers play a crucial role in determining access to reproductive health services and their influence is likely to be heightened in delivering services to HIV infected women (Harries et al., 2007). Future research must first address these perceptions in healthcare workers directly. Particularly, future research should explore whether a lack of knowledge among community healthcare workers in Soweto is, in fact contributing to the negative attitudes perceived by the adolescents in this study. If a lack of knowledge about prevention of MTCT and the right of a mother to

conceive is a contributing factor to provider generated stigma, then a healthcare worker intervention may be successful at curbing these negative attitudes.

In 2008, Wu and colleagues (Wu et al., 2008) reported that service providers subjected to a brief intervention were significantly more likely to report better protection of patients' confidentiality and right to HIV testing, lower levels of negative feelings towards people living with HIV/AIDS, and a more accurate understanding of disease management and prevention. The authors provide evidence that a properly constructed healthcare worker intervention aimed to reduce HIV-related stigma generated within this unique and crucial cohort, may be a successful strategy to achieve desired outcomes.

Theoretical Framework to Consider in Future Research

In 2004, Holzemer and colleagues (Holzemer et al., 2007) conducted 43 focus groups with people living with HIV and healthcare workers from five African countries. The research group identified a framework for understanding HIV-related stigma that included both contextual factors and a theory of the stigma process. Contextual factors included the environment, the healthcare system and the agent. Environmental factors consider cultural, economic, political, legal and the policy arena. Holzemer *et* al. (Holzemer et al., 2007) suggest the healthcare system is a unique contextual factor because of its importance in health care and as a potential site for anti-stigma interventions. Lastly, agents include the individual who may self-stigmatize, family members, work colleagues and community members. Particularly of interest to the research presented in this adolescent study however, is the relationship between the negative attitudes

perceived by healthcare workers in Soweto and the contextual framework proposed by Holzemer *et al* (Holzemer et al., 2007). This relationship should be explored and this framework considered as future research continues in the field of HIV and fertility related stigma.

Additionally, Holzemer and colleagues (Holzemer et al., 2007) proposed a model for the stigma process that includes triggers of stigma, stigmatizing behaviours, types of stigma and the outcomes of stigma. While previous research has focus greatly on testing and disclosure as potential stigma triggers, little research, thus far, has investigated pregnancy in the context of HIV as a potential stigma trigger. This framework should be considered both in terms of the contextual factors is proposes and the stigma process in order to ground future research in validated theory.

REFERENCE LIST

- Barreiro, P., del Romero, J., Leal, M., Hernando, V., Asencio, R., de Mendoza, C., et al. (2006). Natural pregnancies in HIV-serodiscordant couples receiving successful antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndromes* (1999), 43(3), 324-326.
- Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Research in Nursing & Health, 24(6), 518-529.
- City of Johannesburg. (2008). *The making of soweto*. Retrieved 09/24, 2008, from http://www.joburg.org.za/content/view/920/159/
- Cooper, D., Harries, J., Myer, L., Orner, P., Bracken, H., & Zweigenthal, V. (2007). "Life is still going on": Reproductive intentions among HIV-positive women and men in south africa. *Social Science & Medicine (1982), 65*(2), 274-283.
- Corbin, J. M., Strauss, A. L., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Los Angeles: SAGE Publications.
- Craft, S. M., Delaney, R. O., Bautista, D. T., & Serovich, J. M. (2007). Pregnancy decisions among women with HIV. *AIDS and Behavior*, 11(6), 927-935.
- Ezeanolue, E. E., Wodi, A. P., Patel, R., Dieudonne, A., & Oleske, J. M. (2006). Sexual behaviors and procreational intentions of adolescents and young adults with perinatally acquired human immunodeficiency virus infection: Experience of an urban tertiary center. *The Journal of Adolescent Health:* Official Publication of the Society for Adolescent Medicine, 38(6), 719-725.
- Flicker, S., & Guta, A. (2008). Ethical approaches to adolescent participation in sexual health research. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine, 42*(1), 3-10.
- Forsyth, B., Vandormael, A., Kershaw, T., & Grobbelaar, J. (2008). The political context of AIDS-related stigma and knowledge in a south african township community. SAHARA J: Journal of Social Aspects of HIV/AIDS Research Alliance / SAHARA, Human Sciences Research Council, 5(2), 74-82.
- Gay, C. L., & Cohen, M. S. (2008). Antiretrovirals to prevent HIV infection: Preand postexposure prophylaxis. *Current Infectious Disease Reports*, 10(4), 323-331.

- Harries, J., Cooper, D., Myer, L., Bracken, H., Zweigenthal, V., & Orner, P. (2007). Policy maker and health care provider perspectives on reproductive decision-making amongst HIV-infected individuals in south africa. *BMC Public Health, 7*, 282.
- Hentgen, V., Jaureguiberry, S., Ramiliarisoa, A., Andrianantoandro, V., & Belec, M. (2002). Knowledge, attitude and practices of health personnel with regard to HIV/AIDS in tamatave (madagascar). [Connaissances, attitudes et pratiques du personnel de sante en matiere de VIH/SIDA a Tamatave (Madagascar)] *Bulletin De La Societe De Pathologie Exotique (1990)*, 95(2), 103-108.
- Holzemer, W. L., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Dlamini, P. S., et al. (2007). A conceptual model of HIV/AIDS stigma from five African countries. Journal of Advanced Nursing, 58(6), 541-551.
- Joint United Nations Programme on HIV/AIDS. (2008). 2006 report on the global AIDS epidemic. Geneva, Switzerland: Unaids. Retrieved from http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/
- Kaida, A., Andia, I., Maier, M., Strathdee, S. A., Bangsberg, D. R., Spiegel, J., et al. (2006). The potential impact of antiretroviral therapy on fertility in subsaharan africa. *Current HIV/AIDS Reports*, *3*(4), 187-194.
- Kaufman, C. E., de Wet, T., & Stadler, J. (2001). Adolescent pregnancy and parenthood in south africa. *Studies in Family Planning*, 32(2), 147-160.
- Kipp, W., Chacko, S., Laing, L., & Kabagambe, G. (2007). Adolescent reproductive health in uganda: Issues related to access and quality of care. *International Journal of Adolescent Medicine and Health, 19*(4), 383-393.
- Lewis, J. J., Ronsmans, C., Ezeh, A., & Gregson, S. (2004). The population impact of HIV on fertility in sub-saharan africa. *AIDS (London, England), 18 Suppl 2*, S35-43.
- MacPhail, C. L., Pettifor, A., Coates, T., & Rees, H. (2008). "You must do the test to know your status": Attitudes to HIV voluntary counseling and testing for adolescents among south african youth and parents. Health Education & Behavior: The Official Publication of the Society for Public Health Education, 35(1), 87-104.
- Miles, M., & Huberman, M. (1994). Qualitative data analysis: A sourcebook of new methods (2nd ed.). Newbury Park, CA: Sage.
- Myer, L., Morroni, C., & Cooper, D. (2006). Community attitudes towards sexual activity and childbearing by HIV-positive people in south africa. *AIDS Care*, *18*(7), 772-776.

- Myer, L., Morroni, C., & Rebe, K. (2007). Prevalence and determinants of fertility intentions of HIV-infected women and men receiving antiretroviral therapy in south africa. *AIDS Patient Care and STDs*, *21*(4), 278-285.
- National Department of Health, South Africa. (2008). The national HIV and syphilis prevalence survey South Africa.
- Pettifor, A. E., Kleinschmidt, I., Levin, J., Rees, H. V., MacPhail, C., Madikizela-Hlongwa, L., et al. (2005). A community-based study to examine the effect of a youth HIV prevention intervention on young people aged 15-24 in south africa: Results of the baseline survey. *Tropical Medicine & International Health: TM & IH, 10*(10), 971-980.
- Piantadosi, A., Chohan, B., Chohan, V., McClelland, R. S., & Overbaugh, J. (2007). Chronic HIV-1 infection frequently fails to protect against superinfection. *PLoS Pathogens*, *3*(11), e177.
- Sadob, A. E., Fawole, A. O., Sadoh, W. E., Oladimeji, A. O., & Sotiloye, O. S. (2006). Attitude of health-care workers to HIV/AIDS. *African Journal of Reproductive Health*, *10*(1), 39-46.
- Simbayi, L. C., Chauveau, J., & Shisana, O. (2004). Behavioural responses of south african youth to the HIV/AIDS epidemic: A nationwide survey. *AIDS Care*, *16*(5), 605-618.
- Smith, D. M., Richman, D. D., & Little, S. J. (2005). HIV superinfection. *The Journal of Infectious Diseases*, 192(3), 438-444.
- Volmink, J., Siegfried, N. L., van der Merwe, L., & Brocklehurst, P. (2007).

 Antiretrovirals for reducing the risk of mother-to-child transmission of HIV infection. *Cochrane Database of Systematic Reviews (Online), (1)*(1), CD003510.
- Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research*, *16*(4), 547-559.
- Wu, S., Li, L., Wu, Z., Liang, L. J., Cao, H., Yan, Z., et al. (2008). A brief HIV stigma reduction intervention for service providers in china. AIDS Patient Care and STDs, 22(6), 513-520.
- Zaba, B., & Gregson, S. (1998). Measuring the impact of HIV on fertility in Africa. *AIDS (London, England), 12 Suppl 1*, S41-50.